

## Complete Summary

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### GUIDELINE TITLE

Providing a primary care medical home for children and youth with cerebral palsy.

### BIBLIOGRAPHIC SOURCE(S)

Cooley WC. Providing a primary care medical home for children and youth with cerebral palsy. Pediatrics 2004 Oct;114(4):1106-13. [55 references] [PubMed](#)

### GUIDELINE STATUS

This is the current release of the guideline.

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## SCOPE

### DISEASE/CONDITION(S)

Cerebral palsy

### GUIDELINE CATEGORY

Counseling  
 Diagnosis  
 Management  
 Screening

## CLINICAL SPECIALTY

Family Practice  
Neurology  
Nursing  
Pediatrics

## INTENDED USERS

Advanced Practice Nurses  
Allied Health Personnel  
Health Care Providers  
Health Plans  
Managed Care Organizations  
Nurses  
Physician Assistants  
Physicians

## GUIDELINE OBJECTIVE(S)

- To improve the overall quality of care of individuals with cerebral palsy and their families
- To review the aspects of care specific to cerebral palsy that a medical home should provide beyond the routine health maintenance, preventive care, and anticipatory guidance needed by all children
- To provide guidance on communication and comanagement with pediatric subspecialists and pediatric surgical specialists, therapists, and community developmental and educational teams
- To highlight the value of a primary care medical home from which care is initiated, coordinated, and monitored and with which families can form a reliable alliance for information, support, and advocacy from the time of diagnosis through the transition to adulthood

## TARGET POPULATION

Children and youth with cerebral palsy and their families

## INTERVENTIONS AND PRACTICES CONSIDERED

### Diagnosis/Screening

1. Developmental screening during well-child care, including persistence of infantile reflexes, delayed appearance of postural and protective reflexes, asymmetrical movements or reflexes, variations in muscle tone, and delays in emergence of motor milestones
2. Rigorous neuromotor examination and standardized instruments measuring neuromotor development
3. Dysmorphology or genetics consultation
4. Brain imaging
5. Gross Motor Function Classification System
6. Referral to a multidisciplinary neuromotor clinic or team

## Management

1. Proactive care coordination
  - Monitoring, interpreting, and orchestrating comanagement with specialists and specialty teams
  - Communicating with therapeutic, educational, family-support, and other community resources
  - Advocacy with payers and providers
  - Pediatric ophthalmologic and audiologic consultation
2. Managing spasticity
  - Integrated physical therapy, orthopedic and orthotic management
  - Medication: benzodiazepines, including diazepam, clonazepam, and clorazepate dipotassium; dantrolene; baclofen; tizanidine hydrochloride; nerve and motor blocks and botulinum toxin
  - Dorsal rhizotomy
  - Nutrition management including gastrostomy tube feeding
  - Management of constipation and urologic difficulties
  - Dental care
  - Pain assessment and management
  - Neuropsychological and psychoeducational assessments
  - Counseling regarding complementary therapies including "hippotherapy" (therapeutic horseback riding); not recommended/unproven therapies such as hyperbaric oxygen, nutritional supplements, "patterning" techniques
3. Long term care
  - Scheduling visits
  - Physical accessibility of facilities
  - Documentation and insurance coding
4. Supporting children, youth, and families
  - Early intervention
  - Respite care
  - Planning for transition to adulthood
  - Financial planning

## MAJOR OUTCOMES CONSIDERED

- Efficacy of intervention strategies on the overall quality of care of affected individuals and their families, on the well-being and realization of potential in children with cerebral palsy, and on family resilience and coping
- Efficacy of management of spasticity on deformity, function, pain, and ease of caregiving

## METHODOLOGY

### METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

#### NUMBER OF SOURCE DOCUMENTS

Not stated

#### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

#### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

#### METHODS USED TO ANALYZE THE EVIDENCE

Review  
Review of Published Meta-Analyses

#### DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

#### METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

#### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

#### COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

#### METHOD OF GUIDELINE VALIDATION

Peer Review

#### DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

### RECOMMENDATIONS

#### MAJOR RECOMMENDATIONS

1. Be aware of risk factors associated with cerebral palsy and incorporate neuromotor screening into routine developmental surveillance.

2. Provide prompt referral for early-intervention services for all children with alterations in motor development without waiting for diagnostic confirmation of cerebral palsy.
3. Partner with parents in the pursuit of a diagnosis and a culturally effective discussion of its implications for health, development, and family life.
4. Include screening for sensory impairments in the care plan for all newly identified children with cerebral palsy; brain imaging should be performed when appropriate.
5. Consider referral to a geneticist or pediatric neurologist in the presence of dysmorphic features, positive family history, or any atypical clinical characteristics.
6. Make your office a medical home that includes services such as care coordination, a written care plan, patient and family education, parent-to-parent referral, and advocacy.
7. After the definitive diagnosis of cerebral palsy, begin comanagement with a multidisciplinary neuromotor team and schedule regular chronic condition management visits in addition to regular preventive medical care.
8. Manage spasticity by using a "ladder" approach, starting with the least invasive interventions and adding treatments as needed.
9. Maintain vigilance for the new onset of comorbid conditions such as seizures, cognitive or learning disabilities, nutritional complications, etc.
10. Advocate with parents to school personnel about appropriate educational and therapeutic strategies including: physical, occupational, and speech therapy; nursing; and adaptive and assistive technology.
11. Be aware of and make timely referrals to community and state agencies providing support and services to which the child and family may be entitled.
12. Be a sensitive and useful resource for families in their exploration of complementary and alternative interventions for cerebral palsy.
13. Solicit feedback from families of children with cerebral palsy about the care and services provided in your office and how they could be improved.
14. Assess the quality of your medical home services for children with cerebral palsy and engage in systematic, incremental efforts to improve them.
15. Begin planning for the transition to adulthood with the child and family as early as possible, but no later than 12 years of age.

#### CLINICAL ALGORITHM(S)

None provided

#### EVIDENCE SUPPORTING THE RECOMMENDATIONS

##### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting each recommendation is not specifically stated.

#### BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

##### POTENTIAL BENEFITS

- Primary care management of cerebral palsy provides an opportunity to implement the medical-home model and improve the overall quality of care of affected individuals and their families.
- Prevention of orthopedic complications, the achievement of alternative means of communication, the optimization of motor skills, and the close monitoring of nutrition and growth have positive effects on the well-being and realization of potential in most children with cerebral palsy. In addition, early responses to family-support needs may enhance resilience and coping and equip families with some of the "marathon skills" that caring for their child may require.
- Active and careful management of spasticity is important to decrease or prevent deformity, promote function, alleviate pain, and increase the ease of caregiving.

## POTENTIAL HARMS

Adverse side effects of medications/treatments:

- Dantrolene - hepatotoxicity, weakness, gastrointestinal distress
- Tizanidine hydrochloride - sedation, dry mouth, hypotension
- Benzodiazepines (diazepam, clonazepam, clorazepate dipotassium) - sedation
- Baclofen - sedation
- Intrathecal baclofen - drug-related (hypotonia, weakness, nausea, vomiting, alteration in bowel and bladder function) and device-related (seroma, infection, catheter problems) complications. The most serious complication may result from overinfusion, usually related to programming errors, which may cause respiratory suppression and reversible coma.
- Gastrostomy tube feeding: excessive weight gain

## QUALIFYING STATEMENTS

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Living with Illness

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

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### ADAPTATION

Not applicable: The guideline was not adapted from another source.

### DATE RELEASED

2004 Oct

### GUIDELINE DEVELOPER(S)

American Academy of Pediatrics - Medical Specialty Society

### SOURCE(S) OF FUNDING

American Academy of Pediatrics

### GUIDELINE COMMITTEE

Committee on Children With Disabilities, 2003-2004

### COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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### FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

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## GUIDELINE AVAILABILITY

Electronic copies: Available from the [American Academy of Pediatrics \(AAP\) Policy Web site](#).

Print copies: Available from American Academy of Pediatrics, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60009-0927.

## AVAILABILITY OF COMPANION DOCUMENTS

None available

## PATIENT RESOURCES

None available

## NGC STATUS

This NGC summary was completed by ECRI on November 18, 2004. The information was verified by the guideline developer on January 3, 2005.

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